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1115 Waiver Recommendations

Although the Institute on Public Policy for People with Disabilities has concerns regarding the timeline for the 1115 waiver, we submit the following recommendations and look forward to working in partnership with the State and HMA to ensure that the implementation enriches the lives of the State's most vulnerable populations.

It is critical to evaluate the structure, design and components of the service delivery system for Individuals with Developmental Disabilities. The current system is inadequate in nearly every objective measure: the number of persons receiving services, the number of individuals on the waiting list, the range of options for residential and day services, reimbursement rates, etc.

The concept paper and draft waiver put a focus on the medical model, a model in which the majority of services for individuals with disabilities simply do not fit. Individuals with disabilities cannot be referred to as "patients" and their disabilities are not something to be managed, but to be supported.

UAT: The goals of the waiver include the use of a functional/medical needs tool, rather than based on disability or condition. This notion is not a bad one, however a

universal functional/medical needs tool, that would fully access the unique needs of an individual with disabilities does not exist.

Movement Away From Sheltered Workshops: The current waiver promotes the provision of "employment" services through large-scale congregate developmental training (DT) programs with a modest flat rate of $12,000 a year if you live in an ICFDD or $10,000 a year if you live in your own home or in a CILA. A flat rate of $10,000 regardless of level of need, which also includes the cost for door-to-door transportation, is antiquated and insufficient to meet individual support needs. This translates into roughly $7.69 an hour for developmental training. To put this in perspective, the state-funded day care rate is currently $14,000 a year and this does not include door-to-door transportation. The waiver must adopt the State's *Employment First* policy and provide incentives for individuals to become employed through the array of employment options: competitive; supported; customized; and, individualized on-site Job supports.

Pathway 1:

The Nursing Facility Closure and Conversion Fund included in the draft should be expanded to specifically include private and public ICF/DDs so that Provider's who are looking to downsize can also utilize this fund to continue to move more individuals into the community in smaller settings.

Pathway 2:

Workforce Development and Training: As the state struggles to close state operated residential facilities and to implement the *Ligas* consent decree, it is

imperative that Illinois design a waiver that allows people with disabilities the dignity of choice and the provision of supports to meet their needs. This care must be provided in an environment in which direct support professionals (DSP) (since you use the acronym later, it should be consistent here) are paid a decent and livable wage. Under the current waiver, DSPs working in the Home-Based Supports program can be paid up to $20 an hour without a special review (as this rate has been indexed to annual increases in social security) However, DSPs working in a CILA or DT program, earn much less rates that has not been increased in years. Index the rates to COLA to allow for sustainable services for the future. This should be evaluated annually and adjusted each year.

Pathway 4:

Assessments: As stated above a UAT (universal assessment tool), would be inappropriate for individuals with DD, to provide truly individualized services and supports, the system must have a better tool than the ICAP to determine level of supports needed. The tool being used to do this in a number of states is the Supports Intensity Scale (SIS). Supplementary scales such as "Assessing Persons with Complex Disabilities – The KMG Fragility Scale" can be used for individuals with complex medical/health care needs. In view of the aging of the population of individuals with DD, the State also should consider using the Health Risk Screening Tool, which can be administered by trained DSP's. This tool is web-based and available for a nominal cost per person per month. These assessments or others like them should be used to assess individuals with complex behavioral or medical

needs, provide a rate based upon individual needs, and allow multiple year rates. We also suggest eliminating the 90-day review process for the add-on for individual support needs, and make that an annual reassessment.

CILA Tax:

The CILA tax or assessment is an extension of a provider tax that is currently on nursing homes, hospitals ICFs and ICF/DDs. The 6% tax is meant to come back to the provider and ultimately raise the rates. The promise of this tax though, relies on the state paying Providers on times, not a safe reliance for providers.

Stable Living Through Supportive Housing:

There are a lot of positive aspects of the waiver for individuals with mental health, some of which could be expanded for individuals with DD including expanding access to housing vouchers to individuals with DD.

Assistive Technology: The national waiver guidelines talk about effective and cost effective technology. The Illinois waiver should better include cost effective assistive technology. CMS allows the purchase of tablets, cell phones, and GPS systems under certain circumstances. We must think in non-traditional ways about how assistive technologies can be best utilized to support individuals in their homes and communities while avoiding institutionalization.

Monitoring: The waiver should allow for the appropriate use of and payment for remote sensors and remote monitoring technology and systems to further increase

the individual's control (with individual consent and rights' protections) of their housing environment and reduce the need for DSP on-site resources.

Rebalancing: The language of the draft waiver application uses specific language about smaller settings, supported employment and meaningful day programs for individuals with disabilities. It is important that providers are supported through the transition away from a system that has gone unchanged for decades. As the remaining SODCs close it is also imperative that any savings not be spread across the populations that would be covered under the universal 1115 waiver, but reinvested in community providers as they continue to expand services for more and more individuals.

Quality: There must be a move from a focus on process indicators to outcome measures for individuals with DD. The Bureau of Quality Management should work with providers and provide training and support. Pennsylvania's model has been recognized as a best practice by CMS and it should be considered. There should be continued transparency.

Interdisciplinary Process: The Institute supports the use of an interdisciplinary team in the development of a plan for each individual. The Administrative Code references this in section 115.230. However, discipline trained staff are not funded under the CILA program. The Individual should also be a part of the planning process and when possible individual-led ISP meetings should be the standard.